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(Inq into better support for carers)



Submission to the House of Representatives
Inquiry into Better Support for Carers

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This submission was prepared by: Carers Australia with input from the Network of Carers Associations

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Contact: **Ms Joan Hughes**
Chief Executive Officer
Carers Australia
Unit 1, 16 Napier Close
DEAKIN ACT 2600

Telephone: 02 6 122 9900

Facsimile: 02 6 122 9999

Email: caa@carersaustralia.com.au

Website: www.carersaustralia.com.au

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A carer's story

In 2007 Carers Australia commissioned the University of Canberra to undertake a qualitative analysis of open-ended responses to the Carer Health and Wellbeing Index Survey. This is one carer's story.

Surveys like this make me sad... then I just get on with life as usual ... expecting nothing different to happen. Why would things change? Never have before ... always the challenge to stay 'balanced' and be 'constructive within life' striving to be 'positive' despite 'overwhelming concern for a future for my disabled adult' which 'petrifies me'.

The future worries me so much ... what will happen to my disabled adult ... how to afford a 'safe and happy' life for her, where will she live, how can I afford her future, will I live long enough to do what I need to do, who will care enough???? I tell myself to keep focused and not worry just now ... and most days I am fine but I know there will be no funding for her ... I know of 'older' mums and days in their 80s and 90s who cannot get funding, they have their disabled children living with them ... some cannot go into aged care because of their situation. So who will help us???

I and a good number of my 'disabled' circle of mums often discuss the horrific choice we might make one day ... we do not want to leave our disabled loved ones here in this world without us. I am crying now because I know how shocking it is to say such a thing. I am a sane and rational person, not depressed or suicidal, or in danger of any self harm, just very stressed about the future.

In the meantime, we struggle to be 'normal'. I have recently taken on a 20hr part-time job which I am going to struggle to keep. I need the job to pay for 'respite/care' in order that my husband and I can go out to dinner or have some time to ourselves ... maybe an overnight break. I recently paid \$350 for a 48 hour respite break, it was lovely and just made me realise how 'not normal' we really are.

Wherever we go ... there is always the 3 of us ... and often our daughter simply does not want to be with us anymore ... she would like to do separate things too. Just to go to dinner We must pay for a carer first ... we have no 'normal' friends anymore They are all travelling and 'empty nesters'. A freedom we simply cannot expect to ever have.

Of course we love our special adult with all our heart ... but still long for some of the things we feel we are missing as a couple.

I also care for my 85 yr old mother who lives alone and has some dementia issues. I do all her cooking ... have an ACAT package for 5 hours per week ... we have a carer Monday – Friday for morning meds but I do the rest. We must pay \$120 per month for this service as my mother owns her own home ... that is her only asset, she receives a basic pension but is struggling to pay her household bills .. she has less than \$1500 in the bank. She does not want to move but she may be forced to do so soon.

My new job will be hard to keep due to all these demands ... Mondays I have to pay for a carer because the disabled daughter is home all day ... it actually costs me more than I earn for this day and I am having trouble finding carers. Working Tuesday – Friday would suit be better but that's not possible. Then there will be the days when I have to deal with sickness with both Mum or my disabled child ... I will not go on, but I feel I am not living ... not really.

I cannot see any real solutions on my horizon ... I am just doing my best.

Thank you for listening.

1 Executive Summary

Carers Australia welcomes the Inquiry into Better Support for Carers. The Inquiry represents an important opportunity to understand carer support needs and the solutions that carers and families are seeking. At the same time, the Standing Committee on Family, Community Housing and Youth is encouraged to consider the issues and decisions that will shape how caring is provided in Australia in 10 and 20 years from now.

1.1 Caring in Australia

In Australia around 2.6 million carers provide support to family members, partners or friends and almost 500,000 of these are primary carers. Carers are from all walks of life and their experiences and needs are diverse. The majority of carers are female and of working age but young carers and ageing carers are significant in number and require specially targeted support. The overwhelming majority of people with support needs live in the community with assistance from carers within their families or close relationships.

Through evidence presented in this submission, we show that carers are not adequately supported in their caring role and have limited opportunity to have a life outside of caring. Choices are minimal and despite the many benefits that flow from their caring, carers often face deteriorating physical and mental health, social exclusion and isolation and financial difficulties as a result of caring. Where carers come from a low socio-economic background or live in rural or remote areas, they can be further disadvantaged in their experience of caring and access to support.

Significant and rapid changes in society make what might seem longer term questions pressing. These trends are well documented – an ageing population, people living longer with disabilities and chronic illnesses, fewer working age people available and willing to care, changing expectations about work and family responsibilities and greater family mobility. Policy makers, decision makers, service systems and families will need to know how to answer the big questions:

- What mix of care do we want? How is it paid for and by whom?
- How are carers supported as partners in the provision of care?
- With the need for care and support growing, how do we supply the workforce for a strong economic future?
- What level of investment is government prepared to make to the formal care systems?

There have been important gains over the past 10 years in recognition and support for carers. More is known about their needs and through raised awareness, there is greater community

readiness to value the contribution carers make. While extremely important, expansion of existing carer-specific support such as information and respite is only a part of the policy and program response needed now. This submission aims to assist the Committee identify practical improvements for the short term and consider the strategic issues that have to be tackled in view of the dramatic changes Australia is facing.

1.2 The contribution and benefits of caring

Carers in Australia contributed an estimated 1.2 billion hours of care in 2005. This is the annual equivalent of \$30.5 billion of formal aged and disability care services in Australia. (Access Economics 2005) However, the worth and value of caring extends way beyond the fact of it being cost effective to government and the community.

Caring prevents early or inappropriate entry to institutional care. People needing support can maintain their independence and quality of life in a familiar environment with assistance from people they know well. Caring, if supported well, can help keep families strong and is part of the glue that holds neighbourhoods and communities together. Caring can be a truly rewarding personal experience for the carer, despite the difficulties they face when there is inadequate support and the circumstances are hard. Caring is part of the reciprocity and mutuality that arises in families and other close relationships. In short, increased investment in support of carers is an investment in strong families, healthy communities and a more inclusive and civilised society

1.3 Priority elements of a national framework

Leadership at the national level through the Council of Australian Governments (COAG), on carer needs and caring will see the overwhelming majority of Australians benefit directly and indirectly. More detailed proposals are included in the body of the submission. In broad terms the priorities are:

- **National leadership on caring and carers** - National legislation and a national policy and action plan.
- **Inclusion of carers** - Formal recognition of carers as partners in care embedded in policy making and service delivery.
- **Choice in balancing care and work** - Workplace reforms that provide job security and flexibility for individuals in balancing work and caring responsibilities and a national education campaign directed to employers.
- **Expansion of the level and range of carer specific support services** – Support for carers in their capacity to care and to maintain their health, emotional and social wellbeing. Key priorities nationally are timely access to information, carer education, counselling, respite care, health care and advocacy.

- **Financial assistance** – Measures to alleviate the costs of caring and reduce economic disadvantage, particularly for families and individuals on low incomes.
- **Integration of support** - Strengthening integration of support available to caring families, including processes for assessment, care planning and service delivery. This needs to be underpinned by a cohesive framework across all levels of government.
- **More funding for the essential service systems** - Ongoing investment in community care systems - disability, home and community care, housing, mental health, aged care and palliative care- and development of new models of alternative care and accommodation that offer real choice for individuals and families.
- **Carer awareness and inclusion by service providers** - Training and education of service providers and professionals to better understand and value family carers and support their participation in care planning and service delivery.
- **National research** - Investment in research that can inform policy and shape good practice across the above priority areas.
- **A longer term vision and strategy for shared responsibility for caring** – Through the taxation review examine measures available to reshape the way caring and the costs of care are shared and borne by families, communities and governments.

1.4 Addressing the needs of specific groups of carers

The carer framework outlined above applies to all carers. However carers in specific population groups have additional needs and these are addressed in Section 8 of our submission. The overarching elements of carer support should be based on the fact that each care situation is unique and that carers are individuals in their own right with their own needs.

2 Introduction

Carers Australia and the Network of Carers Associations welcome the House of Representatives Inquiry into Better Support for Carers. This is an important and timely inquiry from the perspective of Australia's estimated 2.6 million carers. The way a society cares for people with disability, frailty, mental illness, chronic conditions and terminal illnesses is a key measure of that society's values. Carers are the backbone of Australia's health and community care systems and their contribution underpins the overall social and economic wellbeing of individuals, families and communities.

2.1 A window of opportunity

This Inquiry presents a critical opportunity to identify practical strategies to improve support for carers and increase their access to the same rights, opportunities and choices available to other Australians. These include the ability to enjoy optimum health, social and economic wellbeing, to participate in family, social and community life, to have financial security and access to employment and education. Importantly, it means having real choices at different stages of life and in their caring roles.

The committee is to be commended for focusing the inquiry terms of reference on questions that are fundamental to carers and accommodating the specific needs of different carer populations. The terms of reference align well with the priorities which Carers Australia has advocated to the Australian Government in recent years.

However the Inquiry presents another important opportunity for Australia to begin shaping a longer-term vision for how we as a society care. Carers Australia wants a future in which the responsibilities and costs of care are better shared and caring is valued as a reflection of our humanity and a foundation for our social and economic prosperity.

Our future vision places people requiring support and care at the centre of decisions about the supports that work best for them. Families and friends who provide support are recognised as partners in care and are not disadvantaged. Formal services more closely match the preferred care arrangements of the individuals, carers and families who need them and they are funded to levels which assure quality, access and affordability no matter where you live.

Having a vision for caring means that decision makers are in a better position to assess whether steps taken now lead in the right direction. It also helps us to see that some of the solutions are not part of the conventional thinking about 'support' for individuals and families involved in caring.

2.2 About Carers Australia

Carers Australia is the national peak body representing carers. Carers are individuals who provide unpaid care to family members and friends with a disability, mental illness or disorder, chronic condition, terminal illness or who are frail.

Carers Australia seeks to lead change and action for carers through:

- being the national voice for carers
- research, policy development and advocacy
- carer services and programs
- education and training for carers and service providers.

We work toward two important strategic outcomes of relevance to this Inquiry:

- carers enjoy improved health, wellbeing, resilience and financial security
- caring is recognised as a shared responsibility of family, community, business and government.

The members of Carers Australia are the state and territory Carers Associations that deliver specialist information, advisory and counselling services to carers in communities around Australia. The state associations also play an advocacy and policy development role in their state or territory and work closely with government and other partners to achieve support and change for carers and their families.

Carers Australia is informed about carer issues through its member Carers Associations, local and overseas research and its participation in national and international forums.

Carers Australia places great importance on the direct voices and experience of carers as well as relying on evidence provided through research and evaluation. The Network gathers and analyses information from carer services, individual advocacy and representation and consultation about needs and preferred solutions.

2.3 Our submission

This submission is informed by Carers Australia's work with and on behalf of carers over many years. It presents a profile of Australian carers and then follows the Committee's terms of reference. On each of the substantive topics the submission presents current evidence, the main issues and priorities for action. The terms of reference identify key carer populations for specific focus. We have included three additional carer populations – sole parent carers, rural and remote carers and carers of people with mental illness because of their particular needs.

The Network of Carers Associations has, over a long period of time, called for action in five priority areas:

- integrated support for carers
- carer financial security
- carer workforce participation
- carer health and wellbeing
- carer education and training.

Included in this submission are strategies to improve the lives of carers across the above priority areas. Carer health and wellbeing is inextricably linked to the independence and wellbeing of the individuals needing support, positive family relationships and strong communities. Hence some of the strategies address wider issues that may on the surface appear tangential to the Committee's terms of reference.

3 Profile of Australia's carers

3.1 Carers now

Australia has almost 2.6 million carers and almost 500,000 of these are primary carers (ABS 2004). Carers are from all walks of life and their experiences and needs are diverse. They can come into the caring journey at various stages throughout their life.

3.1.1 Snapshot of the diversity of carers

The Australian Bureau of Statistics has identified:

- 101,600 carers under the age of 15
- 170,636 carers under the age of 18
- 336,000 carers under the age of 25
- 454,000 carers over the age of 65
- almost 2 million carers are of workforce age (18-64 years) (ABS 2004)
- 31,500 Indigenous carers over the age of 25 (ABS 2008)
- 660,000 carers born outside Australia (ABS 2003)
- 337,000 carers born in mainly non-English speaking countries (ABS 2003).

The ABS data on disability also reflects the contribution of carers.

- Over 3 million Australians live with limitations arising from disability or ageing.
- 79 per cent of people with a disability who live in households receive care from relatives and friends, mainly partners, parents or children.

- 1.25 million people have a disability that results in profound or severe limitations. Of this group, 1.07 million people (85.6 per cent) live in private households.
- 64 per cent of primary carers over the age of 15 caring for a person with a profound core activity limitation spend more than 40 hours per week caring.
- Individual carers on average contribute 104 hours per week caring for a person with a mental illness (ABS 2004).

Caring is rarely chosen but the majority of carers want to provide or contribute to the care of a family member or friend. The most frequently cited reasons for caring include a sense of family responsibility, a belief that they can provide a better quality of care, a perceived emotional obligation, or simply that there was no alternative available (ABS 2004).

Caring for a disabled child

...However, the driving force of my caring experience is the ability to make a difference to the experience for my disabled child. This is limitlessly rewarding, though intangible. Unfortunately it is also sapping my resources very rapidly because I am so isolated in this experience.

3.2 Looking ahead

The projected rapid ageing of Australia's population is well known. This represents a key challenge for governments and communities in the design and shape of Australia's future health and community care systems and how to achieve the right balance between formal and informal care. It is clear that many more Australians will require care because of age related disabilities.

The number of people with disabilities requiring care will increase over the next 50 years as the population ages (ABS 2004). Two factors are at work here, people living longer and acquiring disabilities and people with existing disabilities living longer. Medical and scientific advances are a factor across the age spectrum, improving the life chances and longevity of people born with disabilities and those acquiring disability as a result of accident or illness.

The National Centre for Social and Economic Modelling (NATSEM) also identifies large projected increases in the ageing disabled population but a steady fall in the number of people available to care. They estimate there will be a 160 per cent increase in the number of people over 65 needing care from 539,000 people in 2001 to 1,390,000 in 2031. This compares with a 25 per cent projected increase for people less than 65 years (NATSEM 2004).

Against this trend, NATSEM predicts there will be a diminishing "caretaker ratio" - the ratio of the number of people likely to provide care to the number of people anticipated to require care. In 2000 the ratio was 2.5. NATSEM estimates that over the next 50 years the ratio will fall below one. (NATSEM 2004 and AMP. NATSEM 2006).

These trends have extremely important implications for policy and program design in the future and for the resources likely to be needed to support formal and informal care.

4 Role and contribution of carers

4.1 The facts

With over 2.6 million carers providing care for family members and friends it is not hard to describe the importance of their contribution:

- people needing care can remain at home in a familiar environment with people they love and who have their interests at the centre of considerations
- carers provide care in a highly individual and flexible way
- carers support family members with disabilities or illness to maximise their life and independence in the community
- family structures and relationships are preserved
- family members or friends experience a quality of care, not always possible in institutional settings.

The contribution of carers adds a dimension to Australian society that is not always valued or recognised.

Carer Payment (child) Review Taskforce 2008

...The caring role is one of immense social and economic value. It cannot be overemphasised that the care provided is often the difference between life and death.

Over the past 20 years policies and programs for people with disabilities, people with mental illness and older people have been premised on the assumption and fact that care in a normal community setting with family and other support is preferable to institutional care. However the shift from institutional models of care has not been matched by adequate development and resourcing of appropriate health and community care

services. Choice about how care is provided within families or other community settings is extremely limited. Nor has there been adequate attention to the financial impact of caring and the costs of care – to carers and the wider community.

The health and social benefits listed above are widely understood by governments, in families and in the community at large. However, until recently Australia has not had data to demonstrate the significant economic value of the contribution of carers and the opportunity costs associated with carers leaving the workforce or reducing their employment.

Access Economics (2005) estimated that carers provided 1.2 billion hours of care in 2005. This is the annual equivalent of \$30.5 billion of formal aged and disability care services in Australia. The value of carers' contributions is not matched by government-funded services and income support payments. This net benefit to the Australian economy often comes at a great

cost to carers and their families. Access Economics estimated that the cost to carers through lost wages was \$4.9 billion annually.

Professor Bettina Cass (2006) said in relation to the Access Economics figures that *“What is not costed here is the diminution of leisure time, as well as employment time and the costs to health and wellbeing.”* The impact of caring on the health and wellbeing of carers is covered in Section 6.

4.2 The main issues

Over the past decade the role and contribution of carers has become better understood and carers have gained some recognition for their role in the health and community care systems. There are more carer specific services, although availability is very uneven and the supply does not come close to meeting current demand.

It is not a matter of choosing family carers or formal services. Both are critical and the way they interact is central to fulfilling the social and economic goals that governments seek to achieve in communities. Yet there is a long way to go.

4.2.1 The case for national leadership

A decade ago Australia was at the forefront of emerging policy and initiatives for carers. Carers Australia believes that, despite some positive initiatives, Australia’s rate of progress has slipped compared with some other Western countries and that strategic leadership at the national level is again needed.

The Inquiry terms of reference rightly emphasise the need for policy and strategy in relation to recognition, access to opportunities and choice, workforce participation and support for carers.

For strategies in these areas to have any chance of success there are some foundational national issues to be acted upon that cannot be dealt with at a program or departmental level.

4.2.2 National recognition and focus on carers

Carer legislation, carer policies and/or action plans have been introduced in all states and territories and some overseas countries. This action is a vehicle for enhancing and embedding recognition of carers and in some cases conferring rights or provisions within existing legislation. Despite calls for a national approach, there is no existing commitment to develop carer legislation and policy at the national level.

National carer legislation could guide interventions and protect rights in four key areas: carer recognition, participation and rights at work, having mandated involvement as partners in health and community care services and access to certain key supports and entitlements.

More discussion is needed as to the right model of legislation for Australia, drawing on experience elsewhere. Whether it is one act or more and/or reform to existing legislation is a question about the best form of legislation. However to demonstrate true recognition for the role and contribution of carers, national carer legislation is needed.

4.2.3 A coordinating mechanism across government portfolios

Carer issues and policies sit across many government portfolios. There is currently no framework to assist departments achieve coherence across policy and program initiatives. Also there is no vehicle for coordinating a broad national carer strategy or action plan. This is a perpetual challenge for governments. There is a considerable body of experience concerning whole of government coordination and policy formulation that can be drawn upon. Carers Australia has previously advocated for a National Office for Carers. The optimal location of this office is with the Department of Prime Minister and Cabinet in line with its strategic influence and coordinating role across government.

The Federal Government has established an Office for Work and Family and one option is that the Office for Carers be located within this structure. However the Government is also in the process of developing its social inclusion agenda and strategy and it may be that a future Social Inclusion Unit is established. This may be an alternative structure within which an Office for Carers could be situated.

4.2.4 Recognition of carers

With the shifts from institutional care to care at home and the trend to shorter hospital stays, carers are increasingly required to manage the complex health and care needs of people with chronic conditions, disability, mental illness and terminal illness. The cost of the provision of formal services, especially acute health care, residential care and other supported accommodation options is a further factor that contributes to the load borne by family carers.

It is critically important to acknowledge that existing policy relies on the availability and willingness of carers to continue to care and assumes people are generally equipped for the caring role. Section 6 of this submission presents extensive evidence about the impacts of caring on carers' health and wellbeing. To fulfil their roles, carers need continuing access to health and other formal care systems. This may be for themselves or for the person for whom they care. In a model that values carers and supports shared care, formal services will supplement care at home, provide choice in how care is arranged within families and provide respite and other support to carers when needed.

Making these arrangements work for the person needing support and the carer requires governments and services to recognise carers as essential partners in managing health and care needs. It means respect for their knowledge and their understanding of what is required, always alongside consideration of the views and needs of the person they care for, the wider

family context and professional assessments that are made. It also requires specific services and assistance for carers to support their capacity to care and ensure they have the knowledge required.

A national carer strategy must include recognition of carers as partners in the health and community care systems and include measures to ensure this model becomes embedded in practice. Investment in training of service providers and professionals is needed. Education and training of carers to support their preparedness to care and deal with the range of responsibilities is also an essential component of the partnership model.. The third strand of this strategy involves the development and evaluation of good practice care models and services built on the principle of shared care and partnership. The Guide to Good Practice developed by the Network of Carers Associations in 2007 is a very useful starting point for training service providers and research into and development of good practice models.

4.2.5 National research to underpin future policy development

Until recently there has been very little Australian research to draw on to understand the support needs of carers and inform policy and program development. This issue is identified by other research bodies that have had some involvement to date, including the Australian Institute for Health and Welfare, Deakin University, University of Canberra, the Australian Institute for Family Studies, Taskforce on Costs of Care, the University of Wollongong and other national advocacy organisations in the disability, aged care, mental health and health areas.

Carers Australia has recommended over a number of years an expansion of funding for national research and better mechanisms for coordinating and disseminating available research. At the same time there is an urgent need to improve the national data collection systems to inform future program planning.

A coordinated, national research agenda should be developed as part of a national carer action plan. Priority areas for national research are:

- health and wellbeing of carers
- carers and workforce participation
- adequacy and targeting of income support and the impact of different pensions and payments on caring and workforce participation
- comparative costs and benefits of carer support services
- development of new community care models and long-term financing options for community care
- understanding the needs of specific carer population groups and care situations.

**University of Wollongong –
Effective Caring Report 2007**

...Identifying the needs of Australian carers, and producing and using the best available evidence to meet their needs, is a national priority and there is a role for the research community in building that priority into health and social policy.

4.2.6 Independent monitoring of carer experiences

Carers need an independent watchdog at the national level. At present there is no mechanism for carers to raise grievances or complaints about their experience as service users or care partners. Consideration of the appropriate model is a matter for consultation during the process of developing national carer legislation and policy. Ideally, such a position would be independent of government but have legislated power to inform and influence government decision making with respect to carers. Possible models include:

- a dedicated Commissioner within the Human Rights and Equal Opportunity Commission
- an independent Carer Commissioner established under specific carer legislation, along the line of Children’s Commissioners at the state level
- a Carer Ombudsman position within the Commonwealth Ombudsman’s Office.

4.3 What’s needed?

A national carer framework

- A National Carer Action Plan which includes national carer legislation and policy providing for carer recognition and shared responsibility.
- A National Office for Carers within the Department of Prime Minister and Cabinet to guide policy and programs across portfolios.
- An independent watchdog for carers at the national level, established through legislation.

Inclusion of carers as partners in care

- Recognition of carers as partners in health and community care - across hospitals and community health, disability, aged care, mental health, palliative care and community care service systems.
- A national program of education for health professionals and service providers to better understand carers as partners in health and care management.

National research supporting reforms

- Establishment of a National Carer Research Centre and Clearing House to improve coordination and dissemination of carer research.
- A national Carer Research Agenda that addresses the priority issues around caring.

5 Social and economic participation for carers

5.1 The facts

Recent research on health and wellbeing of carers establishes that caring has major impacts on family and social relationships, participation in community life and participation in work.

There is now a growing body of work that shows primary carers leave their jobs to care, reduce their hours or accept more low skilled work in order to gain some flexibility in hours. This has obvious financial consequences for caring families. Further, employers currently do not provide adequate flexibility of hours, job protection and leave to accommodate caring needs and it is difficult to get time out from paid work for episodic care. There is also considerable evidence to suggest many carers want the choice to work but feel there are limited choices available to them.

5.1.1 Workforce participation

Research by the AIHW (2004) showed that primary carers are less likely to be employed than people of the same age in the community.

- 47 per cent of male primary carers aged 25–54 years were employed full-time compared with 80 per cent of men who were not primary carers
- 18 per cent of female primary carers aged 25–54 years were in full-time paid employment compared with 39 per cent per cent of women not caring.

Caring for her husband

..One becomes accustomed and adjusts to the circumstances. We are always together, our leisure is reading. My husband is very dependant so I don't get time out to do things by myself. He is always THERE! Sometimes I could scream. But he is a good man so I have adjusted.

Further, AIHW has projected that by 2013, 265,200 of primary carers between the ages of 25-29 will be women.

Of these, 121,900 (46%) will be unemployed or not in the labour force. Of the projected 96,400 male primary carers in 2013, 43,400 will be unemployed or not in the labour force (AIHW 2003).

The Taskforce on Care Costs has produced a number of reports on the impacts of care costs on workforce participation. (2005; 2006; 2007) The Taskforce found the cost of care was a major factor in employees with caring responsibilities leaving the workforce (1 in 4) or reducing their hours (1 in 4). It also found 35 per cent of employees with care responsibilities would increase their hours of work if care was more affordable. Nearly half (44%) of working carers had selected a role at work below their skill level because it provided greater flexibility. Costs of care can also impact on relationships at work.

Researchers at the University of NSW Social Policy Research Centre analysed the data from the 2006 Families Caring for a Person with a Disability Survey of 1002 carers on Carer Payment

and Carer Allowance. Their analysis focused on women and workforce participation (Gray, Edwards and Zmijewski, 2008) Key findings were:

- 47.1 per cent of carers on only the Carer Allowance were in employment, 11.4 per cent full time and 35.7 per cent part time
- for those on Carer Payment, 0.8 per cent were working full-time and 25.2 per cent part-time, or an employment rate of 26 per cent
- 46.3 per cent of carers receiving only the Carer Allowance and 69.5 per cent receiving Carer Payment were not in the labour force
- among those carers not employed, a majority wanted to work (69.6 per cent of those only on Carers Allowance and 53.6 per cent of those receiving Carer Payment) and the desire was stronger among younger carers.

The main reported barriers to finding employment were:

- difficulty in arranging working hours (23 per cent)
- no alternative disability care arrangements (22.4 per cent)
- disruption for the person with the disability (12.7 per cent).

The authors highlight the need for further research on the impacts of caring on workforce participation. They argue there is a need to look at other variables such as who takes on the caring in families, as this may be affected by employment status or earning potential prior to caring. Further, the experience of carers on higher salaries may be different because they are in a better position to purchase care and maintain workforce participation.

The Australian Institute of Family Studies (AIFS) in collaboration with the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) (2008) recently released a report on the impacts of caring based on the data from the survey conducted in 2006 of 1002 carers who receive an Australian Government payment.

In addition to the findings already highlighted, they show:

- many carers stopped work, reduced hours or changed jobs because of their caring responsibilities
- compared with the general population, a higher proportion of carers and their families suffer financial hardship
- many carers had supportive people around them, however a significant minority (one in five) had no close support
- conflict and relationship tensions in caring families was common
- many carers have limited social engagement because of the time associated with caring (60 per cent of carers in the sample cared for more than 100 hours per week).

5.2 The main issues

5.2.1 A shrinking workforce

Australia's rapidly ageing population is a key driver in Australian public policy. As in other industrialised countries, there is concern about the costs of an ageing population coupled with a shrinking workforce. An aspect of this debate is the need to maximise workforce participation (particularly of women aged 35-54 years) and to provide adequate levels of community care for people as they age. Women in the 35-54 age group typically provide this community care. At the same time, the predominantly female aged care workforce is also ageing, and this presents a challenging workforce dilemma for the aged and community care sector and the Federal Government.

At a time when the Federal Government is looking for ways to address the national skills shortage and improve productivity, little attention has been given to a largely under-utilised resource - the almost 2 million carers of workforce age - many of whom want to work.

This will become a much larger issue. One in three Australians surveyed by the Taskforce on Care Costs (2007) expect to care for an aged person and/or a person with a disability in the next five years and workplace flexibility will be what they are looking for to allow them scope to care and stay in the workforce. It is imperative that Governments, employers and services meet this challenge head on with carefully designed policy and strategies.

5.2.2 Enabling choice

In *It's About Time: women, men, work and family* the Human Rights and Equal Opportunity Commission (HREOC 2007) addresses choice for Australian families and the need to remove the legal, policy and social barriers which continue to shape their workforce participation and family arrangements.

For most Australians, work is a central and necessary part of their adult lives. Carers Australia believes that all carers have the right to work should they choose to. It can bring a sense of worth and provides individuals and families with the financial means to carry on their lives and provide for others. Just like other members of the community, many carers value the opportunity to work and want to be a part of the workforce. Carers who are able to find a balance between paid employment and their caring can experience many financial, social and psychological benefits. The family members or friends they support also benefit providing there are high quality services available that can be planned and relied upon.

Employers who support carers benefit from greater stability, skill retention and improved workplace morale, which in turn leads to increased productivity. These gains have flow-on effects to the whole economy.

5.2.3 Supporting carers in the workforce

Adequate and flexible leave, job protection, flexibility with hours and work arrangements are essential elements of employers supporting carers.

Carers' comments in relation to workforce participation

...We need a DVD on 'a day in the life of a carer' to show my work mates so they'll understand I'm not just taking time off for no reason.

...There is too much randomness and arbitrariness with organisations [in relation to flexible work practices for carers]. While I have very supportive people where I work, I hear of plenty of people who don't have that support. There almost needs to be a national charter that has the agreement of Federal Government and organisations.

The Federal Government has just released the National Employment Standards. These recognise the need for maximum flexibility and choice for parents of young children and provide:

- that both parents have the right to separate unpaid leave up to 12 months with the birth of a baby
- where families prefer one parent to take longer leave they will be entitled to request up to an additional 12 months of leave
- parents will be entitled to request flexible work arrangements until their child reaches school age.

To a much lesser extent, and at a very unsatisfactory level, the National Employment Standards recognise the entitlement to unpaid carer's leave. These standards provide:

- an employee with 2 days unpaid carer's leave for each permissible occasion when a member of the employee's immediate family, or a member of the employee's household requires support.

The new national standards do not adequately address standards for family carers in the workforce. New Zealand and the United Kingdom have both introduced legislation which confers carer rights to greater flexibility at work. Carers Australia has previously advocated two specific measures: increasing the Personal/Carer Leave Standard from 10 to 20 days and a new standard of 12 months unpaid leave for carers of people who have a serious or terminal illness.

Legislation is the first step but there is also a need for a concerted campaign and support of employers to embrace and realise the full benefits of these arrangements - for employees and employers through increased productivity and retention in the workplace.

5.2.4 Sharing the costs of care

The Taskforce on Care Costs reports clearly demonstrate that care costs impact on workforce participation as well as financial wellbeing of carers and caring families.

72 per cent of respondents to a 2006 News poll survey of employed carers initiated by the Taskforce considered that care costs should be a joint responsibility of carers or families and the Federal Government. Australians with caring responsibilities are not seeking a welfare handout to meet the costs of care, but a greater and fairer sharing of these costs. The poll found overwhelming support for extending the Child Care Rebate to the care costs of aged care (92 per cent of respondents) and to the care costs of people with a disability or a chronic condition (95 per cent).

The Taskforce recommended the Federal Government fund a 50 per cent reimbursement, up to \$10,000 each year, for disability and aged care costs as a tax rebate as a measure to support workforce participation of carers and family caring. Carers Australia endorses this practical measure as a real opportunity to improve choice for carers and their social and economic participation.

5.2.5 The rhetoric and the reality

The last report from the Task Force on Care Costs (2007) summed up the situation well.

“... although public rhetoric acknowledges the need to help carers of the aged and people with a disability to balance their work and caring responsibilities, in reality tangible support is insufficient and ineffective. This is evident in relation to public policy (e.g. legislation, financial support and service provision) as well as workplace policy and practices.”

The available evidence shows that carers face social and economic exclusion. The services and financial support that would enable greater choice and a better balance between caring responsibilities, work and other social engagement are simply not available to the overwhelming majority of carers.

5.3 What's needed?

For carers to have real choice in their caring, family and work roles and a better chance of maintaining social connections and relationships, a multi-pronged strategy is required. This fits closely with the Federal Government's agendas for work and family, social inclusion and greater equity of opportunity.

Workplace reforms

- Legislation that guarantees minimum employment rights and conditions for carers including flexible working hours, job protection, increased and more flexible leave arrangements, access to unpaid leave and protection against discrimination in the workplace.
- A national information and education campaign directed to employers and employees to raise awareness of the needs of carers and the benefits of employing carers.

Support to care and maintain workforce participation

- A better designed income support system for carers that recognises the dual goals of workforce participation and supporting family carers and reflects the real costs of caring.
- Utilising the "Employment Innovation Fund" already established by government to develop innovative policies and programs to enhance carers labour market participation
- Improved access to quality alternative care.

Access to care planning

- Care planning needs to involve the people needing support, families and key support agencies. Shared care planning should be part of assessment and ongoing case management for individuals with disability, mental illness, chronic illness and terminal illness.

6 Practical measures to better support carers

6.1 The facts

6.1.1 Carers health and wellbeing

Carers experience reduced physical, mental and emotional health once their caring commences. Over time the effects are intensified. The more hours spent caring the greater decline in a carer's health. Reasons for this decline are many, and include:

- the lack of time for carers to maintain their own health
- putting the health and care of the person being cared for first
- a lack of training to prevent injury
- they simply can't afford necessary health care.

Caring for husband

...Most of the money we receive goes on everyday expenses. We do not have credit cards because that wastes money (in interest and fees). What do we do when we have no resources to pay for medical care that we need as a family. I have a shoulder injury and am in constant pain myself. I can't afford ongoing care for myself.

Carers often become disconnected from friends, social networks and other family members because of the time and demands involved with caring.

Caring almost always leaves families and carers worse off financially through reduced income and the costs associated with care. When families have limited financial means on top of the stresses and health risks associated with caring, their health and emotional wellbeing is more significantly affected. The cumulative effect of these issues leaves carers at high risk of developing physical and mental illness, particularly depression.

The largest Australian survey of carers' health and wellbeing was released in October 2007. The survey undertaken by Deakin University, Australian Unity and Carers Australia found that carers have the lowest wellbeing of any population group surveyed so far. The Australian Unity Wellbeing Index (AUWI) measures personal wellbeing in relation to health, personal relationships, safety, standard of living, achieving in life, community connectedness, and future security. It also includes outcome measures taken from the Depression, Anxiety, and Stress Scale. The key findings are summarised below.

- Carers have an average rating on the depression scale that is classified as moderate depression, and over one-third have severe or extremely severe depression.
- Carers are more likely than is normal to be experiencing chronic pain or carrying an injury associated with caring.
- Carers often don't receive treatment for themselves due to lack of time or affordability of care.

- Household income is lower than for the general population and a factor in carers having lower health and psychological wellbeing.
- Carers live with a high level of financial insecurity and worry about being able to afford household essentials and meet expenses.
- Sole parents are the most disadvantaged group of carers.
- Female carers have lower wellbeing than male carers.
- Wellbeing decreases as the hours of care increase.
- Carers living with the person requiring care had the lowest wellbeing score.

The Report by the AIFS and FaHCSIA (2008) finds similar needs among caring families. This report is helpful for its focus on family relationships and support networks and more research of this kind is needed alongside understanding the specific needs of primary carers.

- Carers and their families have higher rates of mental illness, with depression being a major issue.
- Carers are more likely to experience poor physical health.
- Caring families are more likely to experience financial hardship.
- Caring impacts on family relationships and there is often conflict around care arrangements which makes it harder to plan and coordinate informal care. This conflict is often greater in families caring for a person with a psychiatric disability.
- 13 per cent of carers cared for two or three people with a disability and about a third cared for a child along with the person with a disability. In these families mental health is likely to suffer more and depression is common.
- Almost a half of carers did not use any form of support service.

Sole parent carer caring for an autistic son

...I am divorced and caring for a profoundly autistic, non-verbal, violent son. Although I am managing at the moment I find the future daunting. How will I manage to look after my son now he is 18 and getting bigger? How will I get a job after being out of the work force for so long if I am no longer able to care for my son? How will this impact on my health? How will my son manage when I am not around to look after him. These and other concerns play on my mind continually.

6.2 What are carers saying?

In a separate report prepared by University of Canberra and Carers Australia (2007), the qualitative responses in the AUWI survey were analysed and provide a picture of the concerns carers have when thinking about their health and wellbeing. The views are representative of what the Carers Associations hear daily.

- Carers feel their contribution is undervalued and that governments are out of touch with the needs and realities of people with disabilities, others needing support and the families providing care.

- Carers feel time poor and live with constant financial insecurity and worry.
- They believe the Carers Allowance is not enough.
- They believe that more respite services and a wider range of options are needed and that no respite is better than substandard respite.
- Carers are concerned about the lack of suitable alternative accommodation and worry about the time when they can no longer take care of their family member.
- Carers generally put the needs of the person they support ahead of their own needs, often to the detriment of their own health and wellbeing.

6.3 The main issues

6.3.1 A focus on carer health

The evidence above shows that carers are a population at risk of poor health. There is a tendency for general practitioners and health services to focus on the person being cared for and to overlook the health and support needs of carers. A focus on the specific health needs of carers is needed in primary health care services and in the assessment and ongoing case management processes within the disability, community care, aged care, mental health and palliative care service systems.

There are precedents where the Federal Government has introduced health initiatives for specific population groups at risk of poor health, including Better Health Outcomes for Mental Health, the annual health checks for people aged 45-49 years with a health risk and, more recently, the Healthy Kids Check.

The National Health and Hospitals Reform Commission has been established to develop a long-term blueprint for national reforms, develop incentive payments to improve health outcomes and boost the provision of primary health care. A National Preventative Health Taskforce is advising the Commission, governments and health providers on future health prevention strategies. Carers should be a priority target group for the Commission and Taskforce and should be included on any advisory groups set up to determine the shape of a future health system.

Given their poor health status, the Federal Government would benefit from having a group that can advise specifically on the health needs of carers and inclusion of carers as care partners in the health and community care systems. Carers Australia proposes a National Carer Health and Support Taskforce is appointed to assist with future health services planning and reform.

Identification of carers

Identifying carers at the point of contact with primary health care providers is a major issue. The Australian General Practice Network (AGPN 2007) has acknowledged that the health needs of carers are often overlooked due to poor identification rates by medical and allied health professionals. This is particularly the case where the carer presents with the person they support, rather than as a patient.

There is an urgent need to raise awareness among general practitioners and other health professionals across all levels of the health system of the impact of caring on carers' own health and wellbeing. Intervention to support carers maintain their own health is needed. Many people would not identify themselves to health professionals as carers.

AGPN proposed a number of practical measures that would assist with identification and data collection on carers and their health needs:

- a community awareness program targeting primary health care providers and carers
- information management and information technology strategies which facilitate the collection and exchange of secure electronic clinical and patient data along the lines of those in place for chronic disease management
- the inclusion of a carer identification checkbox within the patient profile in all primary health care providers software programs
- expanding the preventative health check for 45–49 year olds Medical Benefit Schedule (MBS) Item to carers
- utilising the MBS Items relating to Chronic Disease Management, Enhanced Primary Care and mental health with carers, on the grounds that they cover conditions experienced by many carers.

Carers Australia has proposed these measures in recent submissions to the Federal Government.

Growing demand for counselling support

The high levels of depression and other mental health issues, requires an urgent response. This could take two forms. Prioritising carers as a target group in their own right in the planning and delivery of mental health services and expanding the National Carer Counselling Program.

The Network of Carers Associations currently delivers the National Carer Counselling Program. During 2006-07 the Network provided 19,109 counselling services to 6,449 carers, an average 2.9 sessions per carer. The demand for counselling continues to grow. However, the current levels of funding are not adequate to meet the needs. Research indicates that the risk of carers and family members experiencing a depressive episode of 6 months or more was

greatest in the first year of caring (AIFS 2008). Increased access to family counselling is also needed given the tension and conflicts that can arise around care planning and management.

Expanding respite care programs

Carer health and emotional wellbeing and capacity to care well are greatly assisted by access to respite care. Respite is also one of the foundations for encouraging carers to maintain or re-establish connections with the workforce, education and other social networks. The specific type and level of respite needed will vary for each care situation.

Demand for respite has grown significantly as the available services and programs have been introduced and become better known. Often the services struggle to provide the level, duration and model of respite that is being sought by families. Flexibility, scope for planned and emergency respite, and respite that meets the needs of the person being supported and the carer are fundamentals of service design.

Investing in services

Carer wellbeing is inextricably linked to the wellbeing of the person they support and the supports they both have in their lives. Access to services such as GPs, home help, personal care, community health, housing, supported accommodation, community transport and specialist services remain central to carers as well as the people they support. Improving the health and wellbeing of carers therefore is also about:

- further investment in Australia's disability, mental health, aged care, home and community care, palliative care and general health services
- improving assessment, care planning and case management processes and designing approaches that put the person needing support at the centre and systematically recognise carers as partners in care
- developing service systems that have capacity to be flexible and individualised to the needs of the person requiring support and their family carers
- investing in research and evaluation to identify and disseminate good practice models and share the findings across service sectors.

6.3.2 Financial security

Caring households are financially less well off than other households, especially those with a primary carer. On average, their gross personal income is more than 25 per cent lower than for non carers. For almost half a million carers, the disparity is more than 40 per cent. (ABS 2003). The research on health and wellbeing and costs of care all show that caring can have an adverse financial impact through reduced income, the costs of care and the costs associated with disability and illness.

Government support payments

As at June 2007, there were 393,263 recipients of Carer Allowance and 116,164 people who were receiving Carer Payment. As at March 2008, the maximum single rate of Carer Payment was \$546.80 and the maximum partnered rate was \$456.80 per person per fortnight. Income testing arrangements mean that carers who participate in the workforce may have their Carer Payment reduced. At the same time, the Carer Allowance was \$100.60 per fortnight. Many carers who receive Carer Payment are also entitled to Carer Allowance. The Carer Payment and Carer Allowance are difficult to obtain because of tight eligibility criteria. Many carers rely on other forms of government income support that may provide less financial support (AIFS 2008).

The Carer Allowance, which is not income or asset tested, is a supplementary payment to eligible carers of a person with a disability, chronic condition, mental illness or who is frail aged. The Carer Allowance is paid in general recognition of the caring role. Carers Australia has continually called on the Federal Government to increase carer financial support to offset some of the additional costs associated with caring.

A Carer Bonus for recipients of the Carer Payment and the Carer Allowance has been announced in the past four Federal Government budgets - \$1,000 for recipients of Carer Payment and \$600 for those on Carer Allowance. The Carer Bonus is much appreciated by carers as it contributes to their capacity to meet some of the larger expenses of caring. However many carers are excluded from this benefit. The bonus is not currently considered income support and there is no guarantee that it will be renewed annually into the future.

Growth in payments

There has been large growth in the number of people accessing Carer Payment and Carer Allowance over the last several years. Consequently expenditure on these programs has increased dramatically. Since 1999-2000, the number of people receiving Carer Payment grew by 145% and expenditure increased by 283%. During the same period, the number of people receiving Carer Allowance increased by 102% and annual expenditure rose by 223% (AIFS 2008).

Deficiencies

The work of the Carer Payment (child) Review Taskforce (FAHCSIA 2008) identifies important deficiencies in current income support arrangements. This includes problems with the eligibility criteria and assessment processes and confusion about the rationale of different payments. The Taskforce report also highlights a lack of recognition of different care arrangements and multiple care responsibilities, payments not reflecting care load or costs and inadequacies in information and services in the community. This report makes a number of important recommendations that Carers Australia supports and refers the Committee to. (See *pages 13-15 of the Carer Payment (child): A New Approach | Report of the Carer Payment (child) Review Taskforce.*)

The development of carer income support policy and payments in Australia has been piecemeal, informed by different policy objectives at different times and resulting in some expansion of entitlement over the years. This is a complex area of national policy and requires consideration of how income support, taxation, superannuation and labour market policies and programs interact. Carers Australia's submission to the upcoming Taxation Review will address these issues in relation to developing a more cohesive framework for income support payments to carers.

Long term financial security

The costs of caring and the associated financial impact can become a life-long disadvantage for carers who leave work to care. They are unable to build up superannuation or any other form of savings and they fall outside the government's existing superannuation measures directed to low income wage earners.

Carers who rely on the Carer Payment and the Carer Allowance for lengthy periods can be particularly disadvantaged with their reduced capacity to save or accumulate superannuation to fund their retirements (AIHW 2006).

Introducing a national superannuation framework for carers was identified by the Australian Human Rights and Equal Opportunity Commission (2007). HREOC's rationale was that Federal Government contributions to superannuation would represent a formal recognition of and compensation for the significant contribution that unpaid caring work makes to national interest objectives such as prosperity and social wellbeing.

A National Carers Superannuation Scheme funded by the Federal Government for carers receiving the Carer Payment and for sole parent carers receiving other income support would assist eligible carers in their long-term financial planning. Carers Australia sees access to superannuation as an issue requiring consideration together with the suggested review of revenue and costs sharing proposals canvassed in the next section.

6.3.3 Housing

Carers Australia's submission to the *Which Way Home – a new approach to homelessness* looked at the emerging policy crisis in terms of the urgent and growing needs of older carers, and their need for alternative forms of accommodation support for their offspring. Our submission also highlighted the concerns of carers regarding long-term, stable and affordable accommodation for themselves and their families. Parents live in fear that their child will become homeless when they are no longer around to care and advocate on their behalf.

If the future community care and health systems are to rely on less institutional care and more home-based care, governments will need to ensure that carers have access to stable, long-term, affordable housing. The vulnerability of carers must be recognised and introduced into affordable housing policy and delivery.

6.3.4 Carer participation and representation

Carers are both service users and care partners at the same time and their experiences and voices are important to policy, program and service delivery processes at many levels.

The right of consumer representatives to participate on committees and forums including those established by government, professional bodies, industry or non government organisations is well accepted. They bring a vital perspective to decision-making processes.

For many years the Federal Government has funded a national health consumer representative program through the Consumers' Health Forum of Australia. Under this program over 200 advisory committees have health consumer representatives. However, there is less recognition of the rights of carers to participate in these forums, and the benefits carers would contribute to advisory bodies. People with disabilities have long advocated that their voice as citizens and consumers needs to be heard directly. The voices of consumers and carers are not interchangeable.

In the mental health area there is greater recognition by governments and service providers of the right of carers to be heard and the value of that contribution. This has been supported by funding through the National Mental Health Strategy. Carers Australia wants to see the establishment of a National Carer Participation and Representation Program, with a focus on national training, selection, support and reporting back from committee processes. Carers Associations have experience in training and supporting carer representatives and this is a strong foundation for such a national initiative. The Network of Carers Associations have a well established infrastructure Australia-wide to coordinate and manage a new program of this type.

6.4 What's needed?

The following priorities for action, together with the strategies outlined in the social and economic wellbeing section, aim to support the health and wellbeing of carers.

Improving carer health

- Early identification of a carer at any level of the health system is an essential first step to their long-term health and wellbeing.
- Investment in carer identification fields in all health systems software.
- Inclusion of carers as a specific population group for health service planning, particularly preventative health and primary health care.
- A National Carer Health and Support Taskforce to advise government on carer health needs.
- A national community awareness campaign to alert primary health care providers and carers to the importance of identifying and addressing carer health needs.
- An extension of some current MBS items to cover carers.

Expanding carer-specific support services

- Increased funding for the National Carer Counselling Program.
- Expansion of respite programs to improve access and allow for greater flexibility in the way respite is tailored to family situations.
- Expansion of carer information and education programs to assist carers prepare for and manage their caring role.
- Services and support programs easily accessible to carers at the outset of their caring responsibilities.
- Increased investment in Australia's disability, mental health, aged care, home and community care, palliative care and general health services as a key strategy for choice and carer wellbeing.
- A National Carer Representation and Advocacy Program that builds capacity for participation of carers in policy, planning and service delivery.

Increasing financial security

- It is essential that the upcoming taxation review investigates and determines a better mix of income support, taxation and labour market measures that assist carers to balance caring and work and at the same time maintain their health, financial security and economic wellbeing.

7 Providing equal opportunity and choices for carers

7.1 Unpacking choice and equal opportunity

To ask how carers might enjoy the same range of choices and opportunities as others in the wider community involves exploration of two questions:

- What rights and opportunities?
- How is equity achieved?

Two further questions arise for policy makers and the community:

- Is the right and opportunity to care one of the choices we truly value as a society and for whom?
- How are the rights and opportunities of carers balanced with providing equal rights and opportunities for people needing support?

In Australia it is generally recognised that everyone should have rights and opportunities in relation to education, health, economic wellbeing, to participate in family, social and community life, to have financial security and to have access to employment. Security in the older years, support for people who are unable to work and support for families are other established rights. Other protections exist against discrimination and abuse for groups typically excluded or vulnerable. Although we aspire to equal access to opportunities in these areas, as a society we don't always deliver and this is the domain of social and economic policies and regulation by governments.

All of the strategies proposed in this submission are directed to providing greater equality of opportunity and choice for carers. They are also concerned with support of the caring situation so that the people involved, carers, people needing support and other family members, experience caring in a positive way.

For carers, choice is multi-dimensional in the context of caring:

- choice to care, and to what extent
- choice to mix care with other life necessities and opportunities such as employment and education
- choice to access formal services and choice about how care is best organised in a particular care situation over time.

The choice to care should not be accompanied by disadvantage or discrimination. Choice is about rights as well as opportunities. One of the difficulties for Australia is that while there are

community standards and some legislative frameworks, we do not have a national Bill of Rights or equivalent human rights legislation. Australia does have laws that provide for rights and protections in certain areas – such as child protection, anti-discrimination, social security, employment and so on. Elsewhere in this submission we have emphasised the importance of carer legislation. Rights and choice are an essential focus for carer legislation.

The rationale for why we need to protect carers' rights and ensure equality of opportunity is multi-dimensional. It's about social justice, basic human rights, freedom to make life choices, community expectations, protection and reciprocity in family relationships.

In arguing the rights and opportunities that should be available to carers, it is critical to recognise that people with disabilities, older people and people with mental health conditions have a right to equal opportunities and choice in their lives. While this is not necessarily at odds with family care, the goals that people needing support have for independence, integration and inclusion need to stand alongside the goals of extending choice and opportunities to carers.

Responsibility for caring needs to be shared across the public and private domains. As a society we need individuals and families to care alongside other state and community provision. The case for shared responsibility is supported by the significant benefits caring brings to individuals, families, communities and how we fare as a nation.

7.2 Benefits of caring

In presenting what's hard about caring, it is easy to overlook the benefits. Despite it being a hard path carers will provide care because it is a very human and familial thing to do. It has intrinsic value within the relationships between people who care about each other. Many carers feel they can provide a better experience for their family member or friend.

The benefits of caring accrue to individuals, carers, families, communities and to the society as a whole.

- Families, couples and close friends can express and deliver on their desire and need to look after and support each other.
- People with disabilities, people with mental illness, people with serious and terminal illnesses and frail older Australians benefit in terms of health, support and their capacity to lead quality lives.
- Caring within families and neighbourhoods keeps people out of institutional care, and prevents people entering such services prematurely or inappropriately.
- Carers can experience the reward of reciprocity in caring. We will all be care givers and care receivers at some point in our life.

- Caring is part of the human capital of communities, it helps ensure everyone has a chance to participate in community life to the maximum level they can.
- Caring by family members and friends is cost effective to taxpayers and Governments.

Caring that is not chosen or supported well can bring adverse impacts that quickly overshadow the positives. Understanding the benefits and risks brings us back to the question of how we provide the right mix of informal and formal care and guarantee quality, flexibility, affordability, and reliability in the options available to carers and their families. Investment in support of carers and their families is cost effective for government in the short and long term. It should not be in place of investment in the mainstream health and community care systems. As a society our social and economic wellbeing is dependent on growth in future funding of formal and informal care.

7.3 What's needed?

A serious and wide ranging debate on these issues is long overdue. At a national level the current policies send mixed signals, at best, about the care choices that we are prepared to make available to individuals and families. The majority of carers and the people they support experience little sense of choice in the current context.

There are significant policy choices to weigh up (Cass 2008):

- Do we commit more public funding to formal care services so that there are alternative forms of care and less reliance on family carers?
- Do we pay or reimburse carers to compensate them for the direct and indirect costs of caring? What are the necessary measures to achieve this – payment for caring as “work”, income support, tax transfers, superannuation and other forms of reimbursement for specific costs?

There are different policy objectives to consider if carers are to have choice and Australia is to fulfil the dual objective of being a country that cares well and achieves a productive and efficient workforce. It involves valuing caring alongside paid work in the labour market.

Investment on both sides is necessary if carers are to have choices across their life course and if people needing support are to also have rights and choices equal to other people in the community.

In the area of families, we can look at the long running debates and shifts in government and community thinking about child care, the policy objectives that sit behind particular provisions and the way costs are shared. Public investment in childcare services is primarily there to support participation in the workforce. It is firmly recognised that parents should be supported to have time out of the workforce to care for young children. However, child care services are

also used as an early education strategy for children and as targeted support to disadvantaged children and families. Policies have a dual focus on parents and children and short and longer term objectives. Protection and quality of care, whether in the home or other forms of care, are firmly established rights in law.

A vision and direction based on shared responsibility

It comes down to the capacity of our society to provide real choices about how the caring is best shared by families, formal services and other informal community support networks. It requires policy makers to think through the full spectrum of supports needed – income support, taxation incentives, superannuation, health and community care services, disability services, mental health services, carer specific support services, housing and accommodation and so on. The policy choices we make in one area can inadvertently devalue caring. Equally other policy choices can value caring but limit people’s access to work, education and leisure. A commitment to quality of care, irrespective of whether it is family or community based, is part of the equation.

How we pay for care will be one of the major challenges for state/territory and federal governments. The predicted demographic changes and the need to maintain a strong economy mean more investment of funds for caring will be needed. The mix of funding, to individuals and the service system, and the contribution that employers might make is all open for policy debate. The federal government however will need to identify potential sources of revenue to fund the increased costs associated with the ageing of the population and the increased need for care and support. There are a number of options that could be considered including:

- utilising the current government surplus to establish a ‘Care Innovation Fund’
- introducing a specific tax levy, potentially linked with Medicare
- introducing a national care insurance scheme or extending the concept of a national disability insurance scheme (currently under discussion)
- or a mix of these measures

In Carers Australia’s view we will be on the right path when the community and governments accept that caring is a shared responsibility.

The UK has just released a national strategy titled *Carers at the heart of the 21st century: a caring system on your side, a life of your own*. (UK Department of Health 2008) The vision statement encapsulates what we believe is a necessary vision for Australia.

“Our vision is that by 2018, carers will be recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet the individual’s needs enabling carers to maintain a balance between their caring responsibilities and life outside caring, whilst enabling the person they support to be a full and equal citizen.”

Importantly, the UK strategy recognises that joint ownership of the vision is essential if it is to be achieved – by central and local government, service providers and other community organisations and carers.

8 Needs of specific carer populations

This section of the submission briefly presents some of the needs and issues facing different carer populations. In being brief, it is difficult to do justice to the diversity of carers and care situations. In practice caring situations include two or more people and the needs in each situation will be influenced by:

- the nature of the support needs and the age and life stage of the person being supported (for example a child with a disability, a young adult with bi-polar disorder, an older person with dementia)
- the age and life stage of the carer/s involved and the relationship to the person being supported (young carer contributing to care of a parent with a disability, older parent caring for an adult child with a disability, sole parent caring for a child with a disability and an ageing parent, male carer caring for his wife with a terminal illness)
- the stage and duration of care – new, short-term, crisis, longer term, life-long – has implications for the issues carers face and the types of responses needed
- where the family or individuals live affects available supports, which in turn affects care options and needs
- being poor when caring commences means there are fewer resources to call on irrespective of your age or the nature of the support needed
- a family or individual’s cultural background influences how caring is perceived and understood and what care arrangement is going to work best in that situation
- in the case of Indigenous carers and communities, cultural factors, poor health status and socio-economic conditions impacting on families and communities add to the level of need and the challenge of finding appropriate responses.

Part of the complexity for policy and program design with respect to carers and caring is that multiple lenses are needed in understanding the issues and locating the solutions.

The Committee has invited comment on the specific needs of new carers, older carers, young carers, carers with multiple care responsibilities and Indigenous carers. Carers Australia has

also included sole parents, rural and remote carers and carers of people with mental illness as carer populations with particular needs requiring specific attention.

There will be many differences in individual care situations because other factors may be more or at least as significant as the fact of being new, young, older or caring for more than one person. The care situation as a whole needs to be understood, including the wider family context.

8.1 Indigenous carers

8.1.1 Needs and issues

On any set of national indicators, Indigenous Australians lag behind other Australians in terms of health, social and economic wellbeing. The situation is well known and documented. An Indigenous child born in Australia today can expect to live 17 years less than a non-Indigenous child (almost 20 years less if they are male). The prevalence of chronic health conditions and disabilities is shamefully high. Many Indigenous communities lack access to basic services such as housing, education, child care and health, and in areas where such services exist, access and opportunities are far from equal.

These issues have been and remain in the national spotlight and the current Federal Government and COAG have made improving outcomes for Indigenous Australians a priority.

8.1.2 Indigenous carers demographics

In 2006, for the first time, the Census collected information on the number of carers aged 15 years or over in Australia. There were 11,600 Indigenous male carers (9%) and 20,000 Indigenous female carers (14%) in 2006. The proportion of Indigenous carers ranged from 8% of those aged 15-24 years, increased to a peak of 15% of those aged 54-54 years, and then decreased to 10% of those aged 65 years and over (ABS 2008).

After adjusting for differences in the age structures of the Indigenous and non-Indigenous populations, Aboriginal and Torres Strait Islander people were more likely than non-Indigenous people to care for another person with disability, long-term illness or problems related to old age (ABS 2008).

8.1.3 Indigenous carers workforce participation

After adjusting for differences in the age structures of the Indigenous and non-Indigenous populations, non-Indigenous carers were around one-and-a-half times more likely to be employed than were Indigenous carers (ABS 2008).

8.1.4 Indigenous carers' need for assistance

In the 2006 Census, around 2,100 Indigenous carers needed help with core activities themselves, of whom more than two-thirds (68%) were under the age of 55 years. Indigenous carers were between one-and-a half and three times as likely as non-Indigenous carers to need assistance with core activities. (ABS 208)

In the light of what is known, it is possible to conclude that Indigenous carers and the people they support are significantly worse off than the majority of caring families. However it is difficult to bring before the Committee precise evidence about the circumstances and needs of Indigenous carers. Caring has not been a specific focus of the considerable research and consultation on needs or the development of national strategies to improve health outcomes and address other aspects of disadvantage and discrimination. There is little documentation of the way in which caring is occurring within communities, who is caring, the resources and supports that people are drawing on, the needs of family members providing care or the extent to which carers and families have access to services.

8.1.5 Current Indigenous carer programs

The Network of Carers Associations delivers some Indigenous carer programs developed with one-off funding from various agencies. However there is no on-going funding to sustain most of the delivery of these programs. For example, Carers NT delivers the "Troopy" Program – an effective respite program through funding from the National Respite for Carers Program. This initiative provides a base of practice knowledge about the delivery of respite in remote Indigenous communities that is invaluable in thinking about services elsewhere. However the remote respite program has insufficient resources to meet the demand in NT and limited capacity to spread this learning to other communities.

8.1.6 Future directions

In December 2007, Carers Australia convened a roundtable with Indigenous elders and Indigenous support workers from Carers Associations to inform thinking about what is needed and consider how the Network might facilitate and assist with the development of strategies to support Indigenous carers, together with Indigenous organisations, leaders and communities.

The Roundtable identified some of the specific characteristics of caring in Indigenous communities and some important principles for further work in this area. These have also been informed by the experience of programs being delivered by state associations.

- It is primarily women and young people who are doing the caring
- Indigenous carers are less likely to see themselves as 'carers' because caring 'for their own' is what they do.
- Family members are likely to be caring for several people across generations.

- People with a disability or mental illness generally have low status in Indigenous communities, and consequently carers also have a low status.
- There are few services and supports in communities to call on, especially in regional and remote centres.
- Many mainstream services are not culturally appropriate or competent, which means in urban centres Indigenous people are unlikely to access the service.

Some of the principles that were important concerning the delivery of services to carers and the people they support were:

- putting Indigenous carers and the people they support at the centre of decision making
- respect for culture, including kinship relationships
- understanding diversity of culture and lifestyles among Indigenous people
- drawing on the resilience that exists in communities
- providing for flexibility in the way support is provided
- partnerships, trust and good relationships make services work
- a long-term planning, funding and service delivery agenda is needed and must be negotiated with Indigenous community representatives and stakeholders.

8.1.7 What's needed

Caring in Indigenous communities and the needs of family carers in those communities deserves to be a priority within Indigenous policy reform and strategy. A long-term approach is needed, just as it is in areas such as Indigenous health, employment and housing. Indigenous carers and the people they support should also be a priority within national developments for mainstream disability, health, mental health, housing and aged care strategies.

More research and data is needed, but on the basis of the data available on health alone, the needs of Indigenous carers and communities are pressing. In the short term, Carers Australia wants to see greater investment in initiatives that can model support for carers and family care situations, alongside other health, disability, mental health, housing and community care strategies. To this end Carers Australia has proposed a National Indigenous Carers and Communities Support Program to enable the development of tailored programs to Indigenous carers with possible components of carer education, flexible respite, integrated assessment and support and training of service providers. New initiatives should be owned by communities, with the potential for partnership models, and action research and evaluation to ensure the learning about good practice can be shared.

Carers Australia recognises that Indigenous communities may have other priorities that they may place ahead of support for carers. Many communities are fighting for access to the basic services and opportunities that other Australians take for granted – health, housing, education

and employment. Better support for carers and the people they support sits alongside these strategies to improve health and wellbeing.

8.2 Sole parent carers

8.2.1 Issues and needs

Carers Australia research in 2005 estimates that there are at least 40,000 sole parent carers based on Centrelink data. Sole parent carers are under a great deal of pressure, economically and socially. Sole parent carers of disabled children have a household income of 46 per cent of the Australian average. They also have significant additional medical costs. For one in four, this represents 20 per cent of their household income. Over half the households with sole parent carers had two or more children. This means that sole parent carers also have caring responsibilities for children without a disability (Stollznow 2005).

For sole parent carers socio-economic disadvantage sits on top of the already significant challenges that face carers of children with disabilities. In sole parent caring families, other family support is often limited or not available. It is not surprising then that the AUWI survey found that sole parent carers had the lowest wellbeing of all carers.

8.2.2 What's needed?

Measures identified to address inadequacies in income support and meeting the costs of care will, if implemented, make a difference to the financial security and emotional wellbeing of sole parent carers.

Sole parent carers rate respite and social support as their two highest priority support needs. For those caring for children with disabilities, frequent quality breaks are necessary to maintain their capacity to care, their personal wellbeing and their long-term health.

Sole parent carers face more barriers than many other income support recipients and family carers in participating in paid work, despite wanting to work. Access to appropriate child care is a major issue, as is access to affordable transport.

Very few sole parent carers currently access Carer Payment, due to the restrictive eligibility criteria and some may not be aware of their eligibility. Carers receiving sole parent payments rather than Carer Payment fall under the work test regime once their child reaches five years of age. All sole parent carers need exemption from the work test regime to allow them to continue their caring role.

There are inequities in the way these different payments operate which add to the difficulties faced by many sole parent carers. These issues should be a priority focus for the taxation review of income support payments.

Further research into the needs of sole parent carers and the best ways to support the care situation, address disadvantage and facilitate the carer's access to social support, education and the workforce is a priority for the proposed national carer research agenda.

8.3 Carers in rural and remote areas

Little research or work has been undertaken around the impact of caring on those in rural and remote areas. We know that as a general population there are issues of access and equity in relation to health care and other support programs for those living in rural and remote areas. These same issues will be faced by those caring for a person with a disability, a person with a mental illness, a frail older person or a person with a terminal illness.

Some work has been done in relation to rural palliative care in response to the needs of those living in these areas to be able live at home for as long as possible. However, more work needs to be done to understand the issues facing those providing care in the home.

Carers in these areas will often not have access to the internet, will need to travel long distances to access health professionals, information and support programs, will need to rely on other relatives or friends to care for other family members and their place of residence while they are travelling and will have additional costs associated with travelling. This has become particularly difficult with the increases in petrol prices.

Research has shown that one third to one half of young carers live in rural and remote areas of Australia.

8.3.1 What's needed

Carers in rural and remote areas of Australia need access to support programs, education and training, information and resources to be delivered by a medium that suits their individual needs and requirements. This could be through the internet, DVDs or in-home support by visiting service providers. It is absolutely critical that when addressing the needs of Australia's carers, the Committee has a particular focus on how best to meet the needs of those carers living outside metropolitan and large regional centres.

8.4 Carers of people with mental illness

The number of people in Australia affected by mental health problems and disorders is significant and continues to grow. Approximately 20 per cent of the adult population and 14 per cent of young people are affected by mental illness in any one year. (AIHW 2006)

Family and other carers are the lynchpin of mental health care in the community. Deinstitutionalisation of mental health services over the past 20 years, coupled with under-resourcing and failure to develop appropriate community care programs means families, carers and friends have borne a significant load in supporting the care, safety and recovery of people with a mental illness or disorders.

Research conducted by the Mental Health Council of Australia (MHCA) and Carers Australia (2000) through focus groups with carers, mental health service providers and stakeholders in each state and territory indicated that individual carers contribute, on average, 104 hours per week caring for a person with a mental illness. For many carers this time includes periods they are “on call” or alert for early warning signs arising with the person they care for.

While the impacts of caring on carers of people with a mental illness are similar to most carers, other factors increase the risks, stress and isolation experienced. These include stigma in the community, the nature of mental illness and likelihood of co-morbid substance misuse, the exclusion of carers by mental health services, and deficiencies in the system. Carers of people with a mental illness can feel traumatised and overwhelmed, and can suffer their own long-term mental health consequences, especially depression, anxiety and stress disorders.

The Committee is referred to research undertaken for the NSW Mental Health program by Carers NSW, to develop the Carer Life Course Framework. The framework identifies six stages (see diagram below) of the caring journey and can be used to anticipate and plan integrated responses to the needs of carers of people with a mental illness (Pagnini 2005). The carer journey moves through similar phases irrespective of the care situation, especially where the

Caring for an adult child with a mental illness

...For carers of people with a mental illness there is the added stress of living within a community which often shows intolerance and lack of understanding towards families (and consumers) where mental illness prevails. We are often given ‘a wide berth’ when we desperately need a friendly chat or even a smile to feel less like aliens.

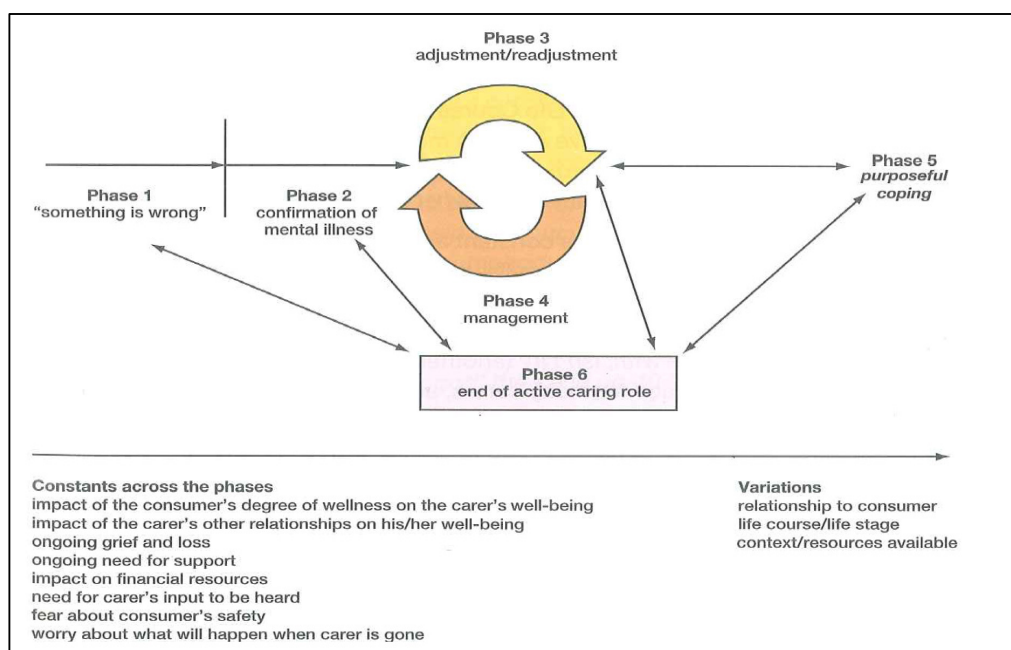
Caring for an adult child with schizophrenia

*...The fluctuating nature of schizophrenia
Coping with paranoia
Watching someone you love unable to fulfil their potential in relation to holding down a job, having loving relationships, being misunderstood by society, negative images of mental illness in the media hurt.
Currently my son is well: I am well – this would change dramatically if he were to have another episode.
I would be depressed, I would isolate myself from others, my quality of life would disappear and I would struggle to cope with the anxiety of wondering would my son survive, recover and get the treatment he needed etc.*

needs are long term. Hence the framework potentially has wider application in helping service providers and carers understand and plan the support required.

Carer Life Course Framework

Although the figure below is shown as a static model at one point in time, caring is a dynamic experience. Some carers spend a great deal of time cycling between phases, especially between Phases 3 and 4. When carers describe their experiences over time, they often use visual analogies such as ‘riding a rollercoaster’ or ‘spiralling’.



Source: Carer Life course Framework: an evidence-based approach to effective carer education and support (March 2005)

8.4.1 What's needed?

Families coping with mental illness want greater certainty of access to a family-focused and ongoing health and care support system, with:

- nationally consistent mental health legislation that recognises and supports carers
- more reliable access to appropriate health and community care support
- alternative supported accommodation services for young adults so they can live independently with the professional support needed
- carer inclusion in assessment and ongoing care planning for their family member and an easier way to deal with the often numerous agencies involved
- respite and counselling to support their capacity to care and to maintain the sometimes very difficult relationships.

As a society we need to look more at what's working. We refer the Committee to an important longitudinal evaluation of the Housing and Accommodation Support Initiative undertaken by the Social Policy Research Centre.

The program being implemented in NSW reflects the above elements and is delivering very positive outcomes for people with mental health problems and their families. (SPRC 2008)

Carers Australia sees the next few years as a strategic opportunity to significantly improve how families and the community cares for people with mental illness. The Department of Health and Ageing (DOHA) and FaHCSIA are currently rolling out the Mental Health Initiative funded from 2007. How and to what extent families are contributing to care and the needs of carers in those families needs to be a priority focus across programs funded under the initiative?

In the light of developments in mental health, there are potentially four roles the Network can play:

- bringing the experience of carers to the many tables deliberating on reform and policy development
- working with government agencies, other key national representative bodies and professional groups to design better service responses that recognise families and carers as partners in care
- providing training and advice to services and professionals on caring and carer issues
- prioritising mental health carers as a target group for counselling, respite, education, training and other support, and seeking funding to allow this to occur.

Since the rollout of the mental health initiative began, the government and community agencies have been seeking the above expertise and advice from the Network. Without additional funding, meeting this demand will be very difficult.

8.5 Young carers

8.5.1 Issues and needs

Young carers are children and young people under 26 years who help care for a family member with a serious health, disability or mental health issue, including alcohol or other drug problems. Data about young carers is limited. We know that there are more than 170,600 Australians under 18 years and 348,700 under the age of 26 contributing to caring for a family member. Of these 41,400 under the age of 18 years and 90,200 under the age of 26 are primary carers. (ABS 2004) Other children and young people assist with care but do not have a primary carer role.

The average age of young carers less than 18 years is 12-13 years (Carers Australia 2002). About three quarters of primary young carers are female. Young carers are representative of the general population in respect of their cultural and ethnic background. One-third to one-half live in the rural and remote areas of Australia where there are fewer services. Young carers are more likely to come from low income families and care is usually for a parent, often with mental health problems. A large number of young carers live in sole parent families.

Young family members are involved in caring because they are the only ones at home available or because caring is shared in families. Most young carers are willing to take on this role providing their families are supported and they can get help when they need it.

The caring role can have significant negative impacts on children and young people. Of major concern is the impact caring can have on their participation and outcomes in secondary and tertiary education. When families aren't well supported, children and young people can miss out on opportunities to go to school, do homework, spend time with friends, have a job or further their studies. Young carers are less likely to complete secondary and tertiary studies compared with other people their age.

Naturally, young carers see themselves as daughters or sons, brothers or sisters who are part of a family rather than a "young carer". A general lack of awareness and focus on the needs of young carers, within schools and among other professionals, means their needs can go unnoticed. They can experience high levels of stress and worry, feel confused, different and uninformed about where to get help. Their physical and mental health can be affected as a result of caring without adequate support.

The issues facing young carers are different and the individual support they need must be oriented to them not becoming disadvantaged in their relationships and education. For the families however the strategies outlined in this submission are the major solution – financial security, access to quality services and support to the family as a whole. Children and young people should not be bearing the load that stems from deficient policies and programs.

8.5.2 What's needed?

Carers Australia has identified three priorities in previous submissions and reports arising from work with young carers:

- a national education and awareness campaign directed to health professionals, education institutions and other services to better understand the impacts of caring and the support available
- expanding the existing support programs targeting young carers to better meet growing demand and broadening their reach so that young people with caring responsibilities and not just primary carers can be assisted

- strengthening the voice of young carers in decision making and planning that affects them through a structured program to support their representation.

The national Supporting Young Carers Program, funded by FaHCSIA and managed and delivered by the Network of Carers Associations, provides direct support to young carers (reaching 8,380 carers since the program commenced); work with schools and other services to sensitise them to carers needs; and, information and training for workers in contact with young carers; and national young carer website.

The total program funding of around \$500,000 per year is seriously inadequate in terms of the growing demand for support. The very success of the program means more is now understood about young carers and more people being referred or seeking help. The program is highly limited in its geographic reach and to date has focused more on young people in secondary school.

The Young Carers 'at risk' Respite Program targets young carers at risk of leaving school prematurely because of their caring responsibilities. The program has two respite components – one for up to five hours at-home respite per week during school term, and the other is two-week blocks of respite to undertake activities such as study, training or recreation. It was designed to complement existing respite programs that are accessible by young carers. However, uptake of other respite services by young carers is very low.

While the demand for the program is high, it is restricted to young carers who are the primary carer. Respite is limited to a maximum of a 12-month continuous period and there are restrictions in the blocks of time and activities that can be supported. Carers Australia has advocated a broadening of the eligibility criteria and greater flexibility in the use of respite which allows the program to focus more on the whole family situation and other young people sharing care. Expansion of funding is also needed, especially given the slow take-up by young carers of other respite programs.

FaHCSIA has reviewed the Supporting Young Carers Program and Young Carers 'at risk' Respite Program. The report as well as the National Young Carer Forum to be held in November 2008 will provide evidence which can be used to reshape this program.

The AIFS report on the nature and impact of caring for family members with a disability in Australia (AIFS 2008) has noted there are unique issues faced by children and young adults who have caring responsibilities for adults or other family members and recommends a study specifically focusing on children who have caring responsibilities.

8.6 Older carers

8.6.1 Issues and needs

The needs of older carers present a particular challenge on a number of fronts. The two most common family situations involving older carers are:

- older carers caring for a son or daughter with disabilities, including psychiatric disabilities
- older carers caring for spouse or partner with dementia, chronic conditions, terminal illness or disabilities resulting from ageing.

Older carers of adult sons and daughters have usually been caring a long time, sometimes as long as 50 years. Long-term caring can take its toll, socially, emotionally, physically and economically. Older carers are caring at a time when their own health may be deteriorating and they are at risk of the normal range of health issues that arise for older Australians. Yet the caring responsibilities do not necessarily diminish or the level of support increase as these issues present.

In addition to the impacts of caring documented in this submission older carers of adult children with disabilities live with anxiety and uncertainty about the future. They fear what is going to happen when they die or become sick and frail and can no longer care.

These older family carers have often given up on the service system because it has failed them in the past. Many continue to care out of love and a sense of responsibility and because alternative supports have not been available to adequate standards or levels. Some family carers have attitudes and identities shaped by their struggle for what they felt was right for their child and against the institutional service models that were available when their sons and daughters were children. They may not be aware of recent developments in service provision, including the carer specific services such as respite that are now available.

In many cases older carers are experiencing the consequences of long term exclusion from the workforce and costs of caring over time. They have little savings or resources to call upon to help them arrange alternative support for the time when they can no longer care or to achieve a different balance of care that recognises their current capacity to care.

An older carer

...I'm not depressed – but I do get down and disheartened. Not because of my family, or looking after them – I love them and will always do what I can – but because of the lack of support we receive from the community. This is from up top in the government and their agencies – right down to my 'friends' and neighbours. Being a carer is an isolating and overwhelming life. Even support groups don't have enough to reach out if you can't reach in. Some days are so hard, and some not so hard – but it is never easy. Having to justify, explain and fight for every step, the double standards we have to endure. It shouldn't be this hard.

It is part of life that in many ageing couples, one partner becomes a carer at some point in time. The person needing support may have dementia, chronic illness, disability or terminal illness and the carer may face health issues of their own. It is not always predictable how and when these care needs arise. Other family support may be available but often adult children are already struggling to balance family responsibilities and employment and may live far from their parents.

8.6.2 What's needed?

These needs arise typically and predictably in the life course of the families involved. The issues demand of us better systems for care planning over time, better alternative services for people with disabilities, including supported independent living options, and different and better options for older couples who have care needs and want to stay together.

It also requires service system responses that can look at the family situation and tailor support to the person with a disability or health condition and other family members involved in their care. This means:

- easy access to information that supports care planning and service access
- inclusive and family oriented care planning processes that respect and cater to the different needs of the people involved
- better models of support and assistance when people need to transfer between different types and levels of care
- having the longer term perspective in planning interventions with adolescents and young adults with a disability
- investment in accommodation and other services that allow people with disabilities to live independently and maintain relationships with family
- dual assessment of older couples where one person requires high levels of support
- in any of these situations attention to the health and wellbeing of people providing care and listening to what it would take to better support their specific care situation.

8.7 Carers with multiple care responsibilities

8.7.1 Issues and needs

Throughout this submission we have acknowledged that many family carers are supporting more than one person. As parents of children with disabilities age and those children become adults, the carer may also be faced with illness, frailty or disability of their parents or partner. Many parents of children with a disability have other children to care for. Some have more than one child with a disability.

In many cases these needs can be predicted (for example, ageing parents). In some cases the additional care responsibilities arise through unforeseen illness or disability. It may be long term.

8.7.2 What's needed?

These examples illustrate the importance of seeing whole family systems and having capacity in the policy and program frameworks to respond to these multiple needs. It means seeing care support as part of a system that sustains families in different ways over the course of people's lives. It also indicates the need to have services that offer maximum flexibility when crises or unforeseen needs arise.

The way programs are currently defined around the needs of a specific person or a specific carer does not always support a systemic and holistic response to family needs. Nor do these programs make transitions for individuals and families easy. The supports and service systems are, as a consequence, experienced by families as being fragmented and ad hoc.

There are many examples of this. People with disabilities and their carers have long advocated the problem that arises when children with disabilities move from the supports available for children and young people to an adult service system. An example was highlighted by the Review of Carer Payment (child) Review Taskforce. When the young person with a disability turns 16, the carer moves to the Carer Payment (adult) but has to undergo a full reassessment the young person's care needs to determine the carer's eligibility, despite the fact that the support needs are unlikely to have changed at all.

8.8 New carers

Carers can come into their caring responsibilities at any stage throughout their life. This could be with the birth of a child with a disability, an accident, the onset of mental illness, the diagnosis of a terminal illness or with an ageing parent becoming frail.

Research clearly identifies the first twelve months as the most critical time in the caring journey. Key findings in the AIFS research on the nature and impact of caring for family members with a disability in Australia include:

- carers and their families experience high rates of mental health problems

New carer

...I found coming into caring that there is not enough information for carers in one format, like a book or folder. I have found out about some services through other carers at times. It would be handy to have it written down or in a similar format in one place. I find you have to ring up people a lot and they give you pamphlets or more phone numbers. It is very time consuming and overwhelming. When you find out someone needs constant care, you don't think about or need certain things straight away. It may be much later. Sometimes you find out about things after you needed them or too late age wise for the person you are caring for.

- 51 per cent of female carers and 30.7 per cent of male carers reported that they had been depressed for 6 months or more since they started caring
- the risk of carers and family members experiencing a depressive episode of 6 months or more was greatest in the first year of caring.

8.8.1 What's needed

A package to support and prepare carers for their care responsibilities at the beginning of their journey is essential. The package should include:

- information and resources
- access to 'time out'
- financial security and planning
- counselling
- education and training
- employment protection where relevant.

Further research is needed to identify the effectiveness of interventions, and how best to deliver these interventions.

9 References and further reading

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